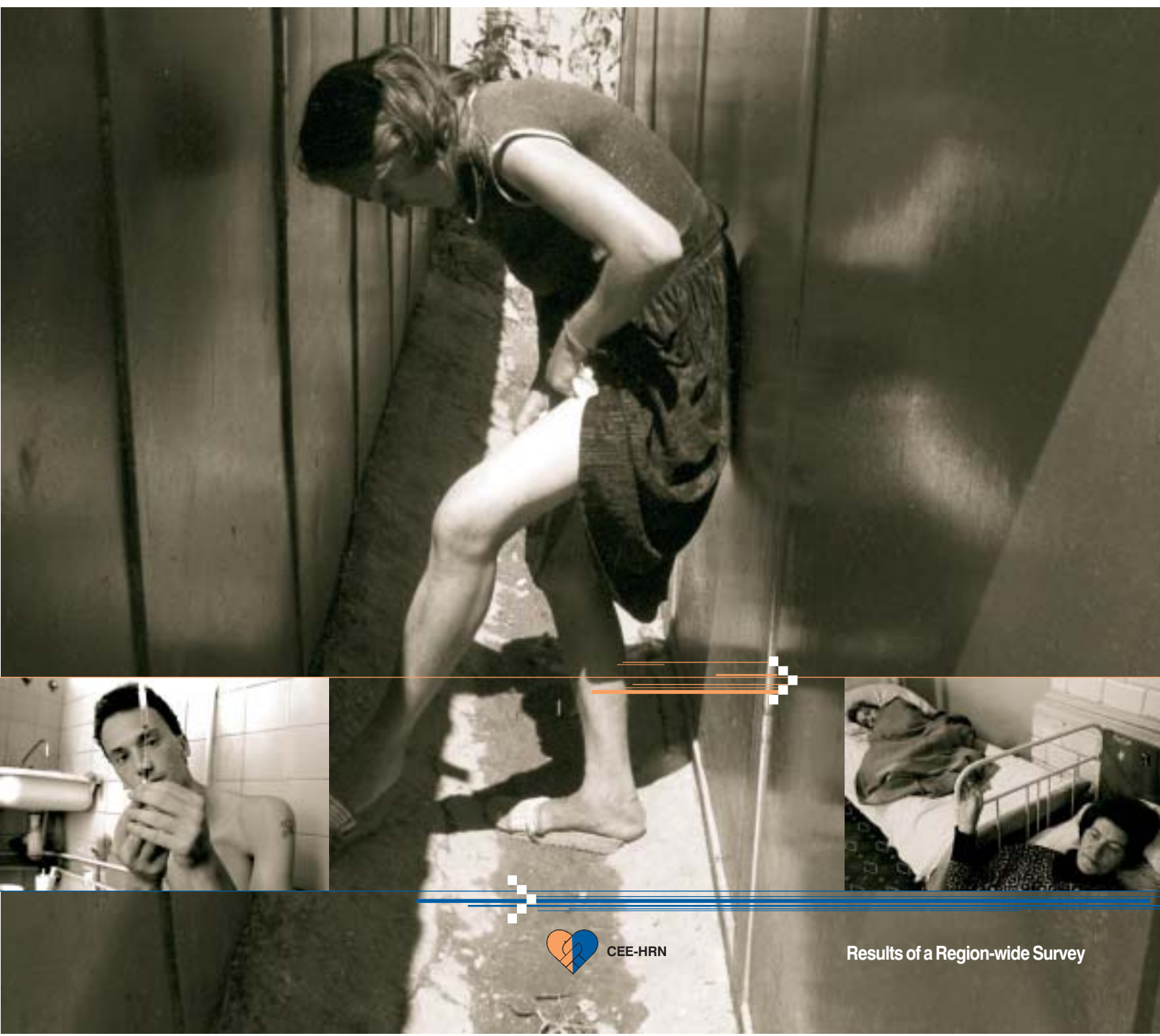


Injecting Drug Users, HIV/AIDS Treatment and Primary Care

➤ in Central and Eastern Europe and the Former Soviet Union



Special thanks are due to the respondents who made this publication possible, and to the people living with HIV courageous enough to share their stories and their expertise.

• Survey Respondents

Country	City or oblast (county)
Albania	Tirana
Armenia	Yerevan
Azerbaijan	Baku
Belarus	Minsk, Mogilev , Svetlogorsk (Gomel oblast), Vitebsk
Bosnia & Herzegovina	Tuzla
Bulgaria	Burgas, Plovdiv, Sofia, Pleven region
Croatia	Dalmacija, Zagreb, Primorsko-goranska county
Czech R	Prague, Usti na Labem
Estonia	Tallinn
Georgia	Tbilisi
Hungary	Budapest, Szeged
Kazakhstan	Aktobe, Almata, Kostanai, Akmolinskaya oblast
Kyrgyzstan	Bishkek
Latvia	Riga
Lithuania	Druskininkai, Klaipeda, Vilnius
Macedonia	Skopje
Moldova	Falesti, Kishinev
Poland	Chorzow, Krakow, Warsaw
Romania	Bucharest
Russia	Barnaul, Khabarovsk, Moscow, Novorossiysk, Penza, Pskov, Saint Petersburg, Tolliati, Tver, Verchniaya Salda, Volgograd, Vologda, Voronezh, Yaroslavl, Yuzhno-Sakhalinsk, Tatarstan Republic, Yakutia, Astrakhan oblast, Irkutskaya oblast, Sverdlovskaya oblast, Saratov oblast, Volgogradskaya oblast, Kaliningrad oblast, Nizhnenovgorod oblast, Altai krai, Lipetsk oblast
Slovakia	Bratislava
Slovenia	Ljubljana
Tajikistan	Dushanbe, Khudjand
Turkmenistan	Ashkhabad
Ukraine	Cherkassy, Khmel'nitski, Kiev, Kremchuk, Krivoi Rog, Lvov, Makeevka, Nikolaev, Odessa, Poltava, Sumy, Autonomus Republic of Crimea, Sumy oblast, Nikolaev oblast, Kirovograd oblast, Ivano-Frankivski oblast, Lvov oblast, Donetsk oblast, Kharkov oblast, Vinnica oblast, Zhytomir, Uzhgorod
Uzbekistan	Tashkent, Termez
Yugoslavia	Belgrade

- **People with HIV:** Oxana, Belarus; Grazina Zakiene, Lithuania; Andrei Artemenko, Russia; Dmitri Barsukov, Russia; Maxim Fedotov, Russia; Yaroslav Kandjuhin, Russia; Stanislav Kazikin, Russia; Sergei Fedorov, Ukraine; Nataliya Leonchuk, Ukraine

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Each year since 1999, the Joint United Nations Programme on HIV/AIDS (UNAIDS) has reported that the HIV/AIDS epidemic is growing faster in the countries of the former Soviet Union (FSU)¹ than anywhere else in the world. In seven years, the epidemic has grown so quickly that there are now more than a million people living with HIV in the former Soviet Union—more than in all of North America. As has also been widely reported, injecting drug users (IDUs) are 88% of all HIV/AIDS cases in the FSU, a fact that raises particular challenges for HIV prevention.

Treatment for HIV— including antiretroviral medication to stop HIV, medications to prevent and treat the infections it causes, and tests to monitor immune damage— has been less discussed. While anecdotal reports have been available from individual countries, there have been few region-wide efforts to collect data or compare approaches. Assessment of particular health care needs of the injecting drug users who make up the majority of those with HIV/AIDS in the region, and the particular challenges HIV-infected IDUs face in accessing care of any kind, including basic health care, has been similarly limited. This report is an effort to break that silence.

Emilis Subata, MD

Coordinator, Central and Eastern European Harm Reduction Network



Executive Summary

A survey of 132 organizations in Central and Eastern Europe and the former Soviet Union (CEE/FSU) assessed the accessibility of HIV medications, basic health care and substitution treatment (e.g., methadone or buprenorphine) for injecting drug users (IDUs) in the region. Organizations surveyed included **harm reduction programs** acting to reduce the negative effects of drug use or to support such efforts (65%), and representatives of **government HIV/AIDS programs** such as national, regional, or municipal AIDS centres, national AIDS commissions, and UN agencies (34%). Among the key findings from survey respondents:

Antiretroviral Treatment (ARV)

Access to antiretroviral treatment (ARV) of any kind, particularly the triple combination therapy considered standard of care by the World Health Organization, is highly limited for all people with HIV across the region.

- Respondents in 24 CEE/FSU countries report that 6 895 people—2% of registered HIV/AIDS cases—are receiving triple combination therapy. More than three-fourths of these are either in Romania (58%), where children infected through medical procedures are receiving treatment subsidized by international aid and medication access initiatives, or in Poland (19%).

- In the European Newly Independent States (Belarus, Moldova, Russia, and Ukraine) only 733 people—0,3% of the more than 250 000 HIV/AIDS cases registered—are receiving triple combination therapy.
- No ARV of any kind is available in Albania, Armenia, Azerbaijan, Kyrgyzstan, Macedonia, Tajikistan, or Turkmenistan.

Access to ARV is even more sharply limited for IDUs, who account for 82% of all HIV/AIDS cases in CEE/FSU countries but only 23% of those receiving any form of ARV.

ARV access is greatest in countries where IDUs are the smallest percentage of HIV/AIDS cases.

- Eight CEE/FSU countries provide ARV to more than 20% of registered HIV/AIDS cases. In all but one, Yugoslavia, IDUs are less than 15% of cases.

Countries where IDUs are two-thirds or more of total HIV/AIDS cases provide almost no ARV of any kind, or exclude IDUs from the little treatment available.

- Of the eleven countries where two-thirds or more of HIV/AIDS cases are among IDUs, none provides ARV of any kind to more than 5% of those infected.

¹ “The former Soviet Union” is used in this report to refer to the Baltic States (Estonia, Latvia, and Lithuania), the countries of the Caucasus and Central Asia (Armenia, Azerbaijan, Georgia, Kazakhstan, Kyrgyzstan, Tajikistan, Turkmenistan, and Uzbekistan), and the European Newly Independent States (Belarus, Moldova, Russia, and Ukraine).

Programs report particularly sharp disparities in access to triple combination therapy for IDUs.

- In Belarus, where 78% of HIV/AIDS cases are IDUs, none are on triple combination therapy.
- While IDUs are 93% of HIV/AIDS cases in Russia, programs report that only 13% of those receiving triple combination therapy are IDUs.

PCP Prophylaxis and CD4+ Monitoring

Medications to prevent AIDS-related pneumonia (PCP) and tests to monitor immune system damage are more accessible than ARV, yet remain out of reach for many in the region.

Twenty one countries report at least some availability of low- or no-cost PCP prophylaxis and CD4+ testing. Only five—Armenia, Azerbaijan, Tajikistan, Turkmenistan and Kyrgyzstan—lack low-cost PCP prophylaxis, CD4+ testing, or both.

Fewer than half (44%) of programs report that their HIV-positive clients have access to low- or no-cost medications to prevent PCP.

Half of programs (50%) report that their HIV-positive clients have access to low- or no-cost CD4+ testing.

Geographical location, even within a single country, sharply affects availability of CD4+ testing and PCP prophylaxis.

- In Ukraine and Belarus, CD4+ testing and PCP prophylaxis are available in the capital cities, but unavailable in the places where HIV prevalence is highest.

Harm reduction programs report sharply lower accessibility of PCP prophylaxis and CD4+ counts than government HIV/AIDS programs do.

- Among harm reduction programs, only one-quarter (25%) said their HIV-positive clients had access to PCP prophylaxis at low or no cost (compared to 78% of government HIV/AIDS programs).
- Only a third (34%) of harm reduction programs said their HIV-positive clients had access to low or no-cost CD4+ counts (compared to 78% of government HIV/AIDS programs).

Primary Care

Free health care is guaranteed in many CEE/FSU countries, and 71% of respondents overall report that some basic care such as treatment of bacterial infections or sexually transmitted diseases is available at minimum or no cost to their clients. IDUs however, appear to face particular difficulties in accessing such care.

Half of programs in the region working directly with IDUs are unable to say how many are receiving primary care.

Harm reduction programs able to indicate how many IDU clients have access to basic health care report that on average, 73% have no access to basic care from any source.

Nearly two-thirds (60%) of harm reduction programs working with IDUs report that drug users are informally discouraged or prohibited from receiving primary health care.

Substitution Treatment

Substitution treatment, proven to reduce drug-related crime, HIV infection, and other diseases, is limited in CEE/FSU countries.

A total of 6 565 patients in CEE/FSU countries are receiving substitution treatment with either methadone or buprenorphine.

- Of these, 6 343 (97%) are on methadone maintenance and 222 (3%) receive buprenorphine.

Where substitution treatment is most accessible, IDUs often represent the smallest percentage of total HIV/AIDS cases.

- 77% of all substitution treatment in CEE/FSU countries is offered in Central and Southeastern European countries where IDUs are less than 15% of total HIV/AIDS cases.
- Croatia and Slovenia alone offer substitution treatment to 3 400 patients, or 52% of all those receiving methadone or buprenorphine in the region.

Where substitution treatment is least accessible, IDUs often represent the highest percentage of total HIV/AIDS cases.

- Nine countries—Albania, Armenia, Azerbaijan, Belarus, Kazakhstan, Russia, Tajikistan, Turkmenistan, and Uzbekistan—offer neither buprenorphine nor methadone maintenance. More than 80% of all HIV-positive IDUs in CEE/FSU live in these nine countries.
- Methadone maintenance, the cheapest and most effective form of substitution treatment, is unavailable in seven of the eleven (64%) countries where IDUs are two-thirds or more of total HIV/AIDS cases.

For Conclusions and Recommendations, please see page 26.

The backdrop: HIV/AIDS cases in Central and Eastern Europe and the countries of the former Soviet Union

“These countries have a good chance, because it is early enough to prevent a big spread of the virus”

Johannes Halleuer, WHO Global Programme on AIDS, 1993

“HIV incidence is rising faster in this region than anywhere in the world.”

AIDS Epidemic Update, UNAIDS, December 2001

The numbers are a lesson in the power of exponential increase. In 2000, more new HIV/AIDS cases were registered in Russia than in all previous years combined. In Ukraine, where fewer than a hundred cases were registered between 1989-1994, an estimated 300 000 are now living with HIV. Cases registered in Estonia increased by 300% in 2001, catapulting the country to one of the highest prevalence rates in Europe. In Central Asia, Kazakhstan reported 185 new HIV/AIDS cases in 1999, 347 in 2000, and 909 in the first nine months of 2001. By May 2002, registered cases had climbed to 2 870.

With the exception of Poland and Yugoslavia, countries in Central and Southeastern Europe have not yet experienced epidemic spread of HIV. In Russia and many other countries of the former Soviet Union (FSU), however, registered infections—which are only a fraction of the actual numbers of those with HIV—are nearly doubling each year. While overall disease burden remains far lower than that experienced by hardest-hit countries in Africa, the HIV/AIDS epidemic in FSU countries—where UNAIDS estimated one million people living with HIV at the end of 2001—is already larger than that of the United States. According to the Imperial College in London, an estimated 5% of Russian adults will be infected in five years, and 4 million will have full-blown AIDS (Walsh 2002).

Further distinguishing the epidemic in the former Soviet Union is the fact that injecting drug users (IDUs) form the vast majority of reported cases and new infections. While many cities or regions of the world have experienced outbreaks driven by drug injection, none have experienced as large and sustained an epidemic among IDUs as in Russia, for example, where 93% of HIV/AIDS cases are attributable to injection drug use (Munro 2002).

High rates of needle sharing, and the fact that drugs in the region are often prepared communally and distributed using a single syringe to fill smaller ones, have made for remarkably rapid increases in HIV prevalence across the FSU (Grund 2001). In Ukraine, for example, HIV infection among IDUs went from

nearly zero in 1994 to more than 50% just two years later (UNAIDS 1999). In Svetlagorsk, Belarus tests of blood in syringes used by IDUs showed that 67% were HIV-infected only a year after the first cases were reported (Grund 2001). In St. Petersburg, prevalence among IDUs was estimated at 0,3% in 1998. By 2000, it was 19,3% (Dehne and Kobyscha 2000).

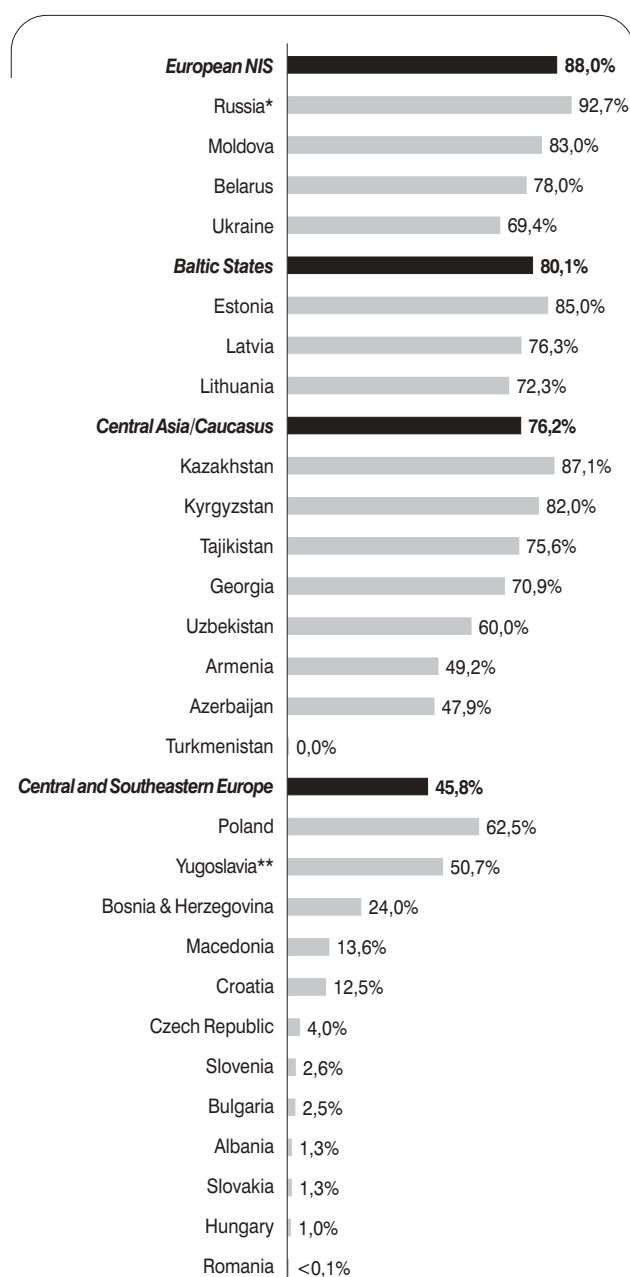
With so many HIV infections attributable to drug injection, penal codes and prison conditions are particularly important factors in the epidemic's spread. In Russia, sharply increasing rates of drug-related arrests and extended periods of pre-trial detention have helped fill cells designed for 28 people with as many as 110 (Stern 1998). Multi-drug resistant tuberculosis, forced sex, and sharing of contaminated injection equipment are common health risks. A recent study in seven Russian prisons found that 21% of prisoners had injected drugs while detained, and 13,5% started injection behind bars (MSF 2000). Officials in Poland estimate that 20% of HIV-infected individuals spent time in prison or pre-trial detention. In Latvia, 20% of total cases—and half of new cases registered each year—are in the prison system (Malinowska-Sempruch 2001). In Lithuania, half as many new HIV/AIDS cases were discovered among prisoners in two weeks of May 2002 as in the entire country in all previous years combined.

The concentration of HIV infection among IDUs and in prison settings could conceivably mean greater ease in controlling the epidemic. Drug users, while not formally organized as a community, are part of semi-formal networks, and thus reachable through structured outreach efforts (Friedman, Des Jarlais et al. 1994). The provision of clean syringes through needle exchange programs has been one of the few HIV prevention interventions consistently proven to reduce infection, in and out of prison (Lurie and Reingold 1993; Paone, Des Jarlais et al. 1995; Alcabes, Beniowski et al. 1999; Finkelstein, Vogel et al. 2000; Jacob and Stöver 2000). Opioid substitution programs, notably those which incorporate methadone in structured maintenance regimens, have also been shown to reduce HIV infection and other drug-related health problems while improving

social function (Ward, Mattick et al. 1994; Lindesmith 1997). Both syringe exchange and methadone have proven effective and achievable in the region, including in prison settings. Slovenia and Kyrgyzstan provide some methadone in prison, and Albania, Estonia and Moldova have begun, on a limited basis, to offer prison-based syringe exchange.

The rise of the HIV/AIDS epidemic, however, has coincided with the decline of many FSU countries'

Figure 1: IDUs as Percent of Registered HIV/AIDS Cases, May 2002



* Russian HIV/AIDS figures as of June 1, 2002. IDU figures as of January 1.

** Yugoslavia data based on AIDS cases - HIV figures unavailable.

ability to implement public health measures. The Soviet system subsidized health care and subjected citizens to rigorous testing and treatment requirements: when the USSR collapsed, so did public health in many areas (Garrett 2000). Workplace health clinics have been privatized (Brown and Rusinova 2000). The obstetricians and gynecologists paid to visit remote areas to provide care no longer make their rounds (Open Society Institute 2001). Massive relocation due to civil conflict and economic hardship—an estimated nine million people in the region were displaced or left voluntarily their homes in the late 1980's and early 1990's alone (Burke 2000)—have disrupted urban infrastructure and torn social safety nets. Public health challenges, from tuberculosis to diphtheria to cholera, have followed closely behind.

Perhaps most importantly as regards HIV transmission, injecting drug use, commercial sex work, and sexually transmitted diseases have all increased sharply. The number of newly reported cases of syphilis in Russia in 2000, for example, was nearly forty times higher than the 1987 rate, with similar increases visible in other FSU countries (UNAIDS 2001). Drug injection has risen at unprecedented levels: in Russia, where addicts are estimated to have increased twelve-fold in the past decade, one recent survey estimated that one half of Russian college students had injected drugs (Kramer 2000). Recent estimates placed the number of commercial sex workers in Moscow alone at as many as 70 000 (Dehne 2002).

Discussion of drug use and sex work often position them as the result of moral failings or existential crisis on the part of individuals searching to determine "who they are" or to cope with rapid social change. This approach is consistent with HIV education approaches generally, which frequently produce accounts that range from the level of the microscopic ("AIDS is caused by a virus carried in blood and semen—it does not discriminate") to the individual ("complacency causes people to have risky sex" or "despair causes people to shoot drugs"). Economic transition, however, must also be seen as a primary engine of drug use, sex work, and HIV transmission. The frequently cited fact that thousands of IDUs in CEE/FSU countries are teenagers is made more comprehensible by a corresponding, less often mentioned fact—by 1999, an estimated 18 million people in the region between the ages of 15-24 had neither school nor employment (UNICEF-ICDC 1999). More generally, a staggering 1/4 of the population in the former Soviet Union was living below the poverty line only eighteen months after the collapse of the USSR (Garrett 2000).

The points of most rapid economic transition are often those where HIV increases fastest. Many of the locations of HIV outbreaks—Narva in Estonia, Temirtau in

Kazakhstan, Nowa Huta in Poland—are in so-called “dead zones,” industrial towns whose enormous Soviet-era factories have been sold off, pared back, or shut down entirely. As formal economies fail, and basic supports such as schools and hospitals close, informal and illegal economies such as drug smuggling and sex work often develop. Similarly, areas enjoying the sudden opening of markets and circulation of goods characteristic of globalization—whether in the free-economic zone of Kaliningrad or urban centers like Moscow and St. Petersburg—have experienced dramatic increases in HIV. Drugs and sex workers are among those “goods” circulating with increasing speed. Further, the open borders and rapid transit characteristic of the global (and post-Soviet) era have helped the HIV/AIDS epidemic broaden from country to country, and from IDUs and sex workers to other groups. In both Ukraine and Belarus, for example, sexual transmission accounted for more than 20% of new HIV/AIDS cases registered last year (UNAIDS 2001).

It is against this backdrop—of rapidly increasing HIV infections, sharply contracting public health resources, and wild extremes of economic transition—that national responses to HIV and the provision of health care in the region must be measured.

Methodology

In April and May of 2002, the Central and Eastern European Harm Reduction Network (CEE-HRN) surveyed its member organizations and other programs working to reduce the spread of HIV and drug-related harm in twenty seven countries of Central and Eastern Europe and the former Soviet Union (CEE/FSU). Using a standardized 42-question survey instrument in Russian and English, CEE-HRN asked about the availability and accessibility of HIV medication, including antiretrovirals, treatment for AIDS-related infections, and medication used to prevent them. In addition, the survey asked about access to basic primary health care for IDUs, and about substitution treatment (e.g., methadone or buprenorphine) used to help them stabilize their behavior and abstain from sharing injection equipment. The survey instrument was developed with technical assistance from the International Harm Reduction Development Program (IHRD), and comments on early drafts were provided by WHO, UNAIDS, and the European AIDS Treatment Group. Survey findings were supplemented by qualitative interviews with people living with HIV/AIDS. Finally, a review of epidemiological reports, medical literature, and interviews with health and substance use professionals were used to help put findings and trends in context.

The survey is the largest ever conducted on IDU access to HIV/AIDS treatment and care in the region. The questionnaire was returned by 132 respondents, from 103 cities, in 27 different countries. As with reported HIV/AIDS cases in the region, the greatest numbers of respondents were in Russia (28, or 21%) and Ukraine (27, or 20%). The majority of respondents (65%) were from **harm reduction programs**: low-threshold projects, funded primarily by foreign agencies or municipalities, working to reduce the negative effects of drug use or to support such efforts. More than a third (34%) of respondents were representatives of **government HIV/AIDS programs**, including national, regional, or municipal AIDS centres, national AIDS commissions and other government and intergovernmental entities such as UN agencies supporting HIV/AIDS treatment and prevention. A significant minority of the government HIV/AIDS programs responding to the survey (12%) also employed harm reduction strategies such as syringe exchange, substitution treatment or other methods to reduce adverse effects of drug use.

Limitations

Sample size. While rate of response and numbers of respondents were high—of 233 questionnaires distributed, 132 (57%) were returned—sample size and

frame both limit ability to generalize from the findings. Drawn from CEE-HRN member organizations, national AIDS centres, UNAIDS focal points, and IHRD grantees, the sample was neither random nor representative. Additionally, in countries like Russia where HIV is now diffused across more than eighty two of eighty nine oblasts (counties), even 28 responses are clearly insufficient to reach statistically valid conclusions about basic health care or antiretroviral treatment nationwide. In several places a response from a single AIDS centre or harm reduction program has had to suffice for an entire country. More focused and detailed research, on the country, city or oblast level, will likely be necessary to develop some of the initial findings suggested here.

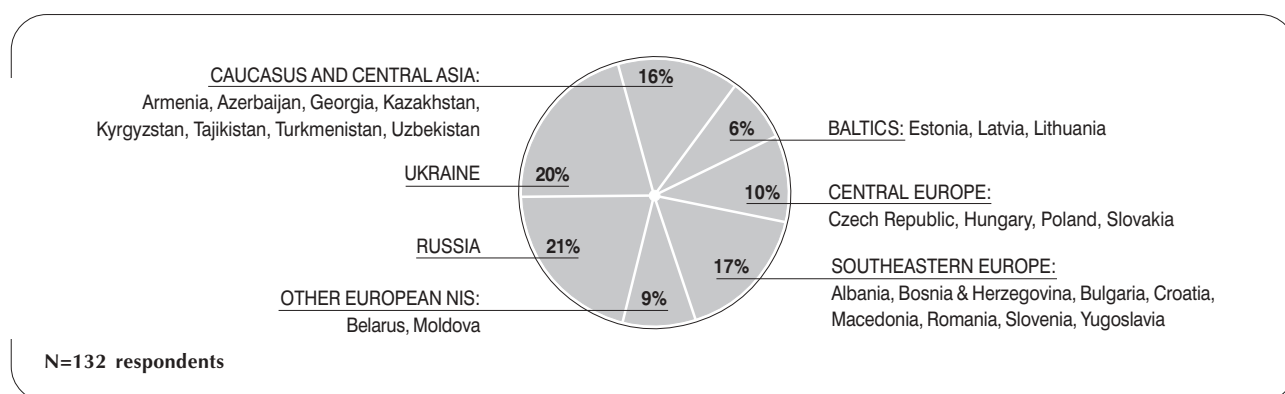
Reporting biases. Programs responding to questions of health care access for their clients—including members of the Central and Eastern European Harm Reduction Network and national AIDS centres—are often among those who advocate most effectively for such care or provide it directly. Consequently, clients of survey respondents may be significantly more likely to receive primary care or HIV/AIDS treatment than others not connected to such organizations. A vast

number of IDUs, many of whom may be HIV-positive, have no access to any form of treatment or organizational support: their needs remain unassessed and unmet.

Additionally, a majority of the programs answering questions about access to health care served IDUs exclusively, a fact that obscured differences between injecting drug users and others in the health care system.

Complexity of health care. Most importantly, questions of health care access are more complex than a brief questionnaire can assess. Responses indicating that “antiretroviral treatment is available at low cost” cannot tell you whether limits are imposed that restrict availability to only a handful of patients, or whether only monotherapy is prescribed. Asking if CD4+ testing is accessible will not tell you whether the tests are reliable, or how often they are used. Similarly, assessing discrimination between injecting drug users and others in primary care is difficult in places where primary care services generally have been radically reduced. As a number of survey respondents and people with HIV noted, it is easy to say that everyone is treated equally if there is little health care available for anyone.

Figure II: Survey Respondents by Sub-region



HIV/AIDS Treatment

Antiretroviral treatment (ARV)

“Although these treatments are not a cure and present new challenges of their own to people living with HIV/AIDS, they have dramatically improved rates of mortality and morbidity, prolonged lives, improved quality of life, revitalized communities and transformed perceptions of HIV/AIDS from a plague to a manageable, chronic illness.”

WHO, *Scaling up retroviral therapy in resource-limited settings: Guidelines for a public health approach*, 2002

An irony of the HIV/AIDS epidemic in Central and Eastern Europe and the former Soviet Union is that it has grown fastest at precisely the same time that HIV-related deaths have dropped most sharply in Western Europe and the United States. Since 1996, antiretroviral treatment (ARV)—specifically the use of three or more antiretroviral medications known as triple combination therapy—has sharply lowered death rates and occurrences of AIDS-related opportunistic infections in the U.S. and Western Europe. Sold for as much as 12 000 USD per person per year in the U.S., triple combination therapy is available for discounts of between 70-90% in a limited number of resource-poor countries through manufacturer discounts facilitated by the United Nations Accelerated Access Initiative, and at sharply lower prices still through generic manufacturers. A year's supply of generic triple combination therapy is now available for as little as 300 USD per person (MSF 2002).

In the majority of CEE/FSU countries, however, triple combination therapy is neither cheaply available nor widely used. While the HIV/AIDS epidemic in some CEE/FSU countries is new enough that relatively few of those infected are likely to require ARV, virtually all CEE/FSU countries have reported AIDS-related deaths—suggesting the need both for ARV and clinical guidelines dictating when and how it should be initiated.

- Access to ARV is best in Central and Southeastern European countries with relatively small epidemics, where some form of ARV is often available to patients at no cost. In Hungary, for example, where 981 HIV/AIDS cases have been registered, a third of these receive some form of ARV free of charge. In Croatia, where 337 HIV/AIDS cases have been registered, 40% receive triple combination therapy for free. This approach is not strictly a function of economic affluence: Bulgaria offers free treatment to all eligible people with HIV.
- In Russia and Ukraine, prices of up to 9 000-10 000 USD per person per year (Hyde 2002; Rühl, Pokrovsky et al. 2002) place triple combination therapy out of reach of many state or municipal budgets and virtually all private individuals infected.
- Russia manufactures its own analogs for AZT, known as thymazide and phosphazide. While the survey did

not specifically ask about the composition of treatment regimens, many Russian respondents indicated that monotherapy with one of these medications was often the only treatment option available.

- An Armenian medication, Armenicum, is undergoing trials for licensing after widespread media reports of high effectiveness against HIV, though no clinical data in internationally recognized medical publications yet supports this claim.
- In Georgia, 3 patients receive generic triple combination therapy imported and paid for by themselves or sponsors.
- In Ukraine, the Accelerated Access Initiative concluded negotiations in May 2002. Under the initiative, four pharmaceutical companies will offer discounts on their products, lowering the annual per person price of some triple combination therapy to 1 600 USD. In a country where average monthly income is approximately 60 USD, and in a time when the same combination is only one-sixth the cost from generic manufacturers, advocates in Ukraine caution that even this price is prohibitive (MSF 2002).

REGIONWIDE, GOVERNMENT HIV/AIDS PROGRAMS RESPONDING TO THE SURVEY REPORT:

The total number of people on any form of ARV, including monotherapy, in CEE/FSU countries is 9 999.²

- Access to ARV is most limited in the Caucasus/Central Asia. No ARV is available in Armenia, Azerbaijan, Kyrgyzstan, Tajikistan, or Turkmenistan.
- No ARV is available in Albania or Macedonia.
- In the European Newly Independent States (Belarus, Moldova, Russia, and Ukraine), only 2 861 people—1% of the 250 211 registered with HIV/AIDS—have access to any form of ARV. Of these, 70% are Russians on monotherapy.

Approximately 6 895 people³ in CEE/FSU countries—2% of registered HIV/AIDS cases—are receiving the triple combination therapy considered standard of care by the World Health Organization⁴.

² No data on ARV is available from Bosnia & Herzegovina. Russian ARV numbers drawn from unofficial estimates provided by staff at the federal AIDS centre. Yugoslavian ARV data based on AIDS cases (HIV data unavailable).

³ No data on triple therapy available from Bosnia & Herzegovina, Bulgaria or Czech Republic.

⁴ The most recent WHO guidelines on retroviral treatment note that even “dual nucleoside drug regimens alone are no longer recommended as they do not adequately suppress HIV replication and are likely to lead to the rapid emergence of resistance.” See *Scaling up retroviral therapy in resource-limited settings: Guidelines for a public health approach*, World Health Organization, Geneva: 2002. p. 11.



Sergei Fedorov, Life Plus, Odessa, Ukraine

I ended up in a narcological (drug treatment) hospital where everyone had to be tested. On the last day, they told me. They had me sign what all people with HIV sign: That I promise to tell to all doctors that I am HIV-positive. That I will keep a separate toothbrush and razor. That I am aware that I can be prosecuted if I infect someone else. They didn't tell me anything about immune system testing, or medications. A psychologist warned me that I might not react normally to the TB test, and gave me an antidepressant.

I didn't go back to the doctors. I went back to drugs. Later, again back at a narcological hospital, I took the HIV test with everyone else once again. I didn't want other people to find out that I was HIV-positive, because those who were infected had to eat alone. After ten days, they served me my breakfast separately and everybody understood.

I have heard many stories of hardships. People with HIV are officially forbidden from working in food handling or at food plants. If someone with HIV needs surgery, they often cannot find doctors willing to perform the operation. One woman, Lena, went to the hospital for a broken arm. She didn't know she was HIV-positive before they tested her there. The doctors threw her out of the hospital when they got the result, saying she should have told them in advance. At the AIDS centre, very seldom can you find antibiotics, much less antiretrovirals. They say antiretroviral treatment is available, but it is available only for a tiny number of people. If you are a drug user, there is a code number on your medical file, and one doctor told me they use the numbers to decide who will receive

medications. Children first, then non-drug users, then drug users.

Others take advantage, saying that they have good treatments—either because they want to try experiments on you, or because they want to make money. One of my friends got some tablets, unmarked, from such a doctor. On the first day she felt badly. On the second day she felt worse. On the third day she lost consciousness.

Even reputable doctors may not do much better. We were looking for a medical consultant to support people with AIDS in Odessa, and asked doctors for their criteria to prescribe antiretroviral therapy. Nobody knew. We did a focus group with inpatients at the AIDS centre: out of thirty patients, no one knew what CD4+ testing was. There is a CD4+ test available at the centre, but it has a 30% error rate. If you want a more accurate test, you have to travel to Kiev, 480 kilometers away, at your own expense, and also to pay for the test. Kiev is the only place to get triple therapy, but at many thousands of dollars per year, the state can only pay for a few. With such a small market many companies don't even bother to pay the registration fee to make their medications available.

The government is acting—our President has spoken about AIDS, there are laws against discrimination, and they are building a new lab in Odessa. But without a special line item in the budget, and commitment from society, government, and people with HIV combined, this cannot be enough. I think of it as a question of human rights. Do we act together? Or do we sacrifice the lives of 300 000 people with HIV?

- More than three-fourths of those on triple combination therapy in CEE/FSU countries are either in Romania (58%), where children infected through medical procedures are receiving treatment subsidized by international aid and medication access initiatives, or in Poland (19%).
- In the European Newly Independent States (Belarus, Moldova, Russia, and Ukraine) only 733 people—0,3% of registered HIV/AIDS cases—are receiving triple combination therapy.
 - In Moldova, where UNAIDS estimated that 5 500 were living with HIV/AIDS at the end of 2001, only one person is receiving triple therapy—through a clinical trial.
 - In Belarus, where UNAIDS estimated 15 000 people with HIV/AIDS at the end of 2001, only two people are receiving triple combination therapy. In Gomel oblast, the region that accounts for more registered HIV/AIDS cases than the rest of the country combined, no antiretroviral treatment at all is available.
 - In Ukraine, only thirty people—roughly one out of every ten thousand thought to be infected—receive triple combination therapy.
 - In Russia, 700 people out of an estimated 700 000 living with HIV/AIDS receive triple combination therapy.
 - No triple combination therapy at all was available in two-thirds of Russian oblasts surveyed.

Figure III: HIV/AIDS, ARV, and IDUs, May 2002

Country	Registered HIV/AIDS cases	Number receiving any ARV	HIV/AIDS cases receiving any ARV (%)	Number receiving triple therapy	HIV/AIDS cases receiving triple therapy (%)	IDUs among registered HIV/AIDS cases (%)	IDUs receiving any ARV	IDUs of those receiving any ARV (%)
Caucasus/Central Asia	5756	68	1,2%	8	0,1%	76,2%	22	N/A
Armenia	189	0	0,0%	-	-	49,2%	-	-
Azerbaijan	389	0	0,0%	-	-	47,9%	-	-
Georgia	316	8	2,5%	8	2,5%	70,9%	4	50,0%
Kazakhstan	2870	30	1,0%	0	0,0%	87,1%	N/A	N/A
Kyrgyzstan	825	0	0,0%	-	-	82,0%	-	-
Tajikistan	45	0	0,0%	-	-	75,6%	-	-
Turkmenistan	2	0	0,0%	-	-	0,0%	-	-
Uzbekistan	1120	30	2,7%	0	0,0%	60,0%	18	60,0%
Central and Southeastern Europe	24472	6924	28,3%	6023	24,6%	22,3%	783	N/A
Albania	78	0	0,0%	-	-	1,3%	-	-
Bosnia & Herzegovina	750	N/A	N/A	N/A	N/A	~24%	N/A	N/A
Bulgaria	373	80	21,4%	N/A	N/A	2,5%	3	3,8%
Croatia	337	135	40,1%	135	40,1%	12,5%	12	8,9%
Czech Republic	525	310	59,0%	N/A	N/A	4,0%	10	3,2%
Hungary	981	326	33,2%	239	24,4%	1,0%	1	0,3%
Macedonia	59	0	0,0%	-	-	13,6%	-	-
Poland	7502	1300	17,3%	1300	17,3%	62,5%	650	50,0%
Romania	12559	4410	35,1%	4010	31,9%	<0,1%	2	<0,1%
Slovakia	157	70	44,6%	58	36,9%	1,3%	2	2,9%
Slovenia	190	73	38,4%	73	38,4%	2,6%	3	4,1%
Yugoslavia *	961	220	22,9%	208	21,6%	50,7%	100	45,5%
Baltic States	4780	146	3,1%	131	2,7%	80,1%	46	31,5%
Estonia	2297	40	1,7%	40	1,7%	85,0%	0	0,0%
Latvia	2035	102	5,0%	87	4,3%	76,3%	46	45,1%
Lithuania	448	4	0,9%	4	0,9%	72,3%	0	0,0%
European NIS	250211	2861	1,1%	733	0,3%	88,0%	1412	49,4%
Belarus	4344	10	0,2%	2	<0,1%	78,0%	2	20,0%
Moldova	1570	1	0,1%	1	0,1%	83,0%	0	0,0%
Russia **	197497	2800	1,4%	700	0,4%	92,7%	1400	50,0%
Ukraine	46800	50	0,1%	30	0,1%	69,4%	10	20,0%
Total	285219	9999	3,5%	6895	2,4%	82,0%	2263	22,6%

As reported by government HIV/AIDS programs

N/A= Data not available

* Yugoslavian AIDS cases as of January 1, 2002. HIV figures unavailable.

** Russian HIV/AIDS cases as of June 1, 2002. IDUs as of January 1. ARV data from unofficial estimates provided by staff at the federal AIDS centre.

ARV and injecting drug users

“It is widely believed that an active dependent drug user may not be able to adhere to a complex regime of antiretroviral treatment. But the makeup of this group of HIV-positive people has never been properly investigated, and its members are in reality not at all homogenous. The degree of drug dependency varies greatly from individual to individual: many have stopped using drugs since they tested HIV-positive and have been clean for several years. Nevertheless, in government HIV statistics they are still considered drug users.”

—Ylenea Purick, MD, *HIV/AIDS News*, International HIV/AIDS Alliance, Ukraine

The World Health Organization, noting that injecting drug users receive the same benefits as others from triple combination therapy, has called for antiretroviral treatment to be made available for IDUs as well as for other patients (WHO 2002). Survey respondents in CEE/FSU countries, however, report that injecting drug users are less likely to receive any form of ARV, including monotherapy, than others with HIV. *“Drug users do not care about life and so do not deserve treatment,”* wrote one respondent, perhaps speaking for many.

Access to ARV is even more sharply limited for IDUs than for others with HIV. IDUs account for 82% of all HIV/AIDS cases in the region but only 23% of those receiving any form of ARV.

ARV access is greatest in countries where IDUs are the smallest percentage of HIV/AIDS cases.

- Eight countries in Central and Southeastern Europe provide ARV to more than 20% of registered HIV/AIDS cases. In all but one, Yugoslavia, IDUs are less than 15% of cases.
- Of the nine countries that provide ARV to IDUs at rates equivalent to their share of national HIV/AIDS cases—Bulgaria, Czech Republic, Croatia, Hungary, Romania, Slovakia, Slovenia, Uzbekistan, and Yugoslavia—eight are in Central and Southeastern Europe.
- Several countries in Central and Southeastern Europe have managed to provide ARV to fairly large numbers of IDUs even when they are a substantial percentage of total HIV/AIDS cases.
 - In Poland, where 63% of HIV/AIDS cases are IDUs, 50% of the 1300 receiving ARV have a history of injecting drug use.
 - In Yugoslavia, where 51% of registered AIDS cases are IDUs, 46% of the 220 receiving ARV are drug users.

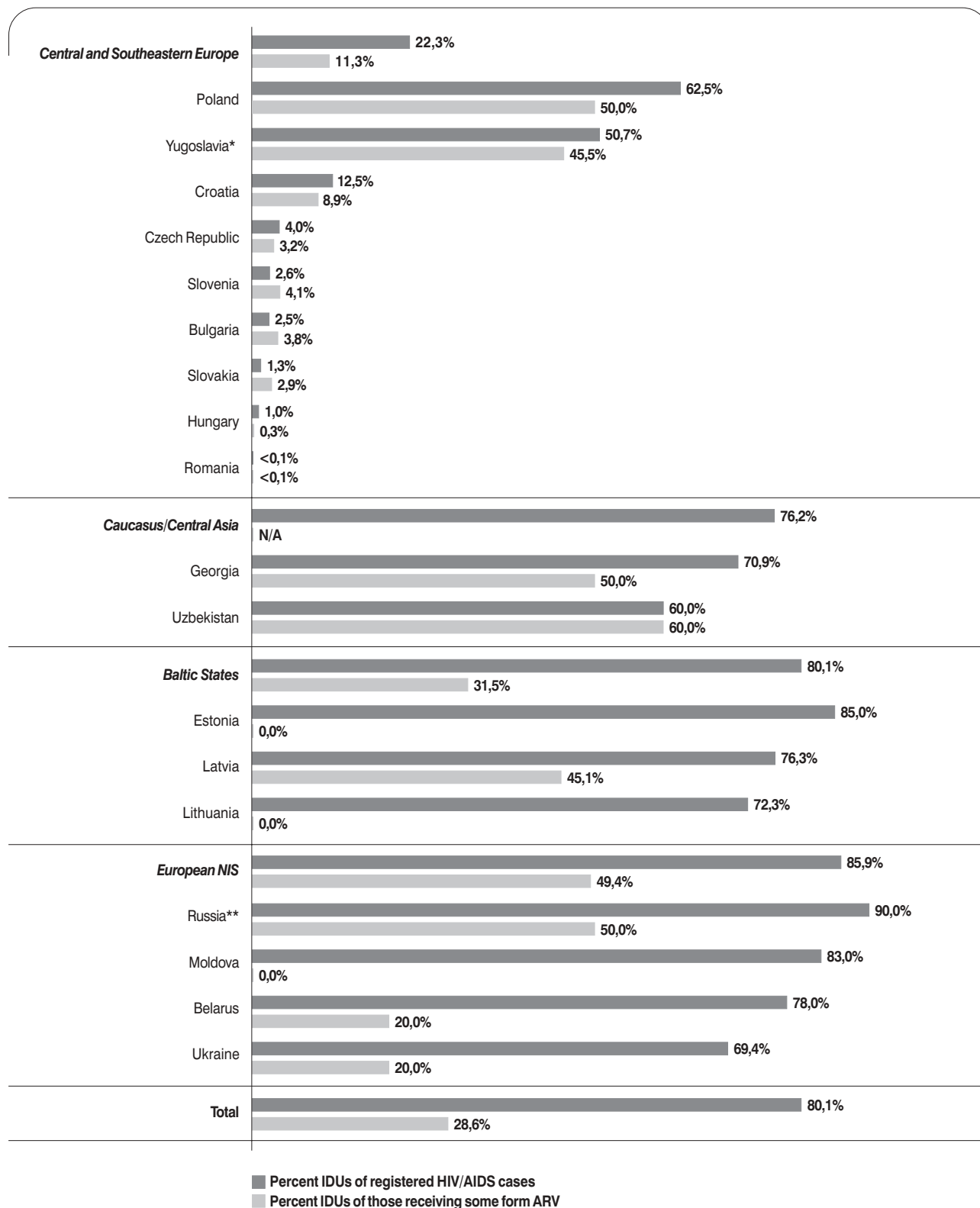
Countries where IDUs are two-thirds or more of total HIV/AIDS cases provide almost no ARV of any kind, or exclude IDUs from the little treatment available.

- Of the 11 countries where two-thirds or more of HIV/AIDS cases are among IDUs, none provides ARV of any kind to more than 5% of those infected.
 - This trend holds true in countries of varied economic prosperity—in Estonia, for example, where estimated per capita GDP in 2001 is 6 670 USD, as well as in Moldova where it is only 2 100 USD (Economist Intelligence Unit 2002).
 - In Kyrgyzstan, where 82% of HIV/AIDS cases are IDUs, no ARV is available at all.
 - In Estonia and Lithuania, where IDUs are 85% and 72% of total HIV/AIDS cases respectively, no IDUs receive ARV of any kind.

Programs report particularly sharp disparities in access to triple combination therapy for IDUs.

- In Kazakhstan, where 87% of HIV/AIDS cases are IDUs, no triple combination therapy is available.
- In Belarus, where 78% of HIV/AIDS cases are IDUs, none are on triple combination therapy.
- While IDUs are 93% of HIV/AIDS cases in Russia, programs report that only 13% of those receiving triple combination therapy are IDUs.
 - In Moscow, respondents indicated that IDUs are restricted by hospital policy from receiving triple combination therapy.
 - In Kaliningrad, where 80% of one program’s HIV-positive clients are IDUs, only 4% of those receiving ARV are. None of those receiving dual or triple therapy are IDUs.
 - In St. Petersburg, where registered HIV/AIDS cases doubled in 2001 and now exceed 15 000 cases, respondents report that only one hundred people are now receiving triple therapy. None of them are IDUs.

Figure IV: IDUs as Percent of HIV/AIDS cases and ARV Recipients (including monotherapy), May 2002



Among countries reporting both ARV availability and IDUs receiving treatment
 N/A= Data not available

* Yugoslavian AIDS cases as of January 1, 2002. HIV figures unavailable.

** Russian HIV/AIDS cases as of June 1, 2002. IDUs as of January 1. ARV data from unofficial estimates provided by staff at the federal AIDS centre.



Stanislav Kazikin, MD, AntiAIDS Foundation, Penza, Russia

As a doctor and a person living for five years with HIV, I may have a special perspective. But it is absolutely clear that the situation in my city is deplorable, even hopeless, for people with HIV. When patients come to the AIDS centre, they receive a diagnosis and a long list of medicines that they are supposed to buy themselves. There is no access to antiretroviral treatment except monotherapy in extreme cases. There is no bacteriological laboratory for proper diagnosis and treatment of opportunistic infections or other complications. There is no viral load testing of plasma. People have no access to medications for prevention of opportunistic infections. And they don't know where to turn.

Doctors are the professionals to whom people with HIV look for help. But how can doctors help when they themselves are unprofessional and afraid? Rather than the concern for the patient that should be foremost, doctors show inaction, ignorance, and neglect. One patient I know was forced to wait for six months for a puncture to drain a serious case of edema. When he was finally hospitalized, they did the procedure in extreme haste, and discharged him with a high fever and no follow-up examination. There is a vicious cycle where doctors will send HIV patients from one doctor to another, and then from that one to the next. It is the appearance of activity, but not really doing anything.

Even basic health monitoring, such as immunograms, are the patient's responsibility. You have to pay 300 rubles (10 USD) for a CD4+ count, which in my case is nearly 20% of my monthly salary. The test is done using primitive technology,

and the laboratory that does the analysis is not connected with the AIDS centre. Many of the very important diagnostic tests needed by HIV-infected people are not provided by the AIDS specialists—when you ask, they say, “you can go and negotiate it, but we can't guarantee anything.”

My own infection forced me out of the field I loved, surgery, into pathology. Even there, my chief told me “I cannot help you develop professionally.” I went to the AIDS centre and offered to work there. I said that I would be willing to see homebound patients, and perform simple surgical procedures. They politely told me that they would consider it, but I never heard from them.

I took the decision to work with an organization doing HIV prevention among drug users and prisoners. The work has been a kind of new education for me. I help people with problems like phlebitis and prevention of complications related to hepatitis. In prison, the situation is particularly bad. Medical personnel are afraid to even bandage the wounds of people with HIV, leaving prisoners to do it themselves.

In my work, where so many are HIV-positive, I can see that even bigger problems are coming. And the inadequacies of the system are not restricted to shortages of tests and medications. Until we as doctors can recognize that people deserve good care no matter how they got infected—and until we can end the stigmatization I see in Penza, where doctors still tell families to isolate relatives with HIV, keep children away from them, and wash all items they touch with bleach—then the health system will never be ready.

PCP prevention and CD4+ testing

While high cost is the largest obstacle for access to ARV, medications to prevent the opportunistic infections associated with HIV/AIDS are much more affordable. Cotrimoxazole, for example, an antibiotic used for the prevention of AIDS-related pneumonia known as *pneumocystis carinii pneumonia* (PCP) and other infections, costs only 8-17 USD a year per patient (UNAIDS 2000). Prophylactic medications are particular useful when combined with immune system monitoring, such as CD4+ counts, used to gauge the strength of a patient's immune response (and if the patient is on ARV, to determine whether it is working). While CD4+ counts are not as cheap as preventive medication—market cost is frequently between 10-20 USD—they are a critical tool in the management of HIV/AIDS and indicate when preventive medication is appropriate to protect against PCP and other serious AIDS-related infections.

While PCP prophylaxis and CD4+ counts are more available than ARV in CEE/FSU countries, they remain out of reach for many.

Some PCP prophylaxis and CD4+ testing is available at low or no cost in 21 countries.

- Only Albania and five Caucasus/Central Asian countries (see box on page 17) report no availability of low- or no-cost CD4+ testing, PCP prophylaxis, or both.

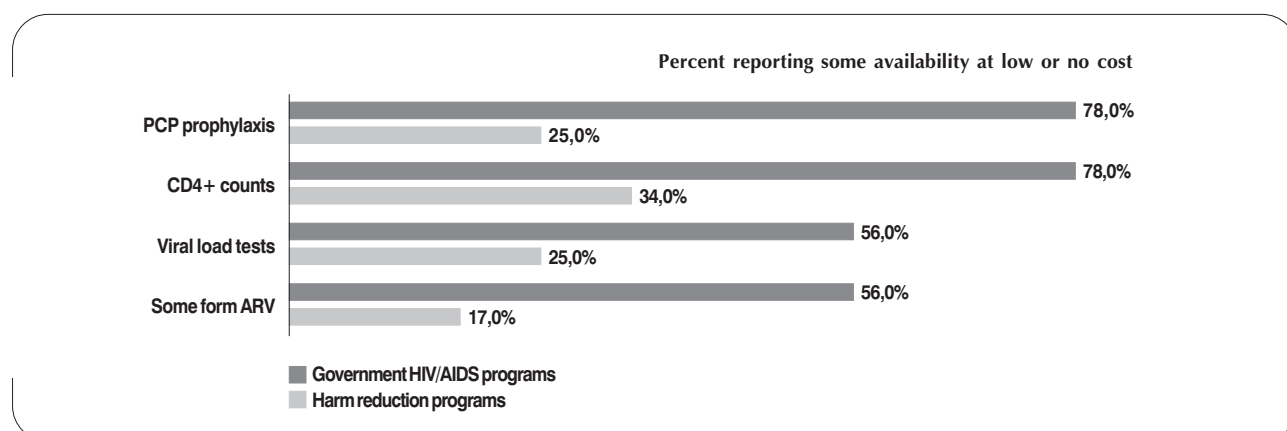
Of 99 programs with HIV-positive clients, fewer than half (44%) report that their clients have access to low- or no-cost medications to prevent opportunistic infections.

Approximately half of programs (49.5%) report that HIV-positive clients have access to low- or no-cost CD4+ testing.

Harm reduction programs report sharply lower accessibility of CD4+ testing and PCP prophylaxis than government HIV/AIDS programs do.

- In all aspects of HIV/AIDS treatment and prophylaxis, harm reduction programs report much more limited access for their HIV-positive clients than government HIV/AIDS programs (see Fig. V).
- Among 60 harm reduction programs serving HIV-positive clients, only one-quarter (25%) said their clients had access to PCP prophylaxis at low or no cost, compared to 78% of government HIV/AIDS programs.
- Among harm reduction programs, only a third (34%) said their clients had access to low or no-cost CD4+ counts, compared to 78% of government HIV/AIDS programs.

Figure V: Government HIV/AIDS Programs vs. Harm Reduction Programs: Reported Accessibility of HIV/AIDS Care and Immune Monitoring





Nataliya Leonchuk, founder, All-Ukrainian Network of People Living with HIV/AIDS

It's hard to say if drug users are discriminated against, because in many hospitals basic things like pain relievers or antibiotics are not available for anyone. But I will admit that when I went for my test, I did not say that I was a drug user. I knew how regular people acted toward drug users, and I did not want the doctors to treat me badly. Even recently—with so many people in our country infected with HIV through drug use—there is a sign hanging on the announcement board of the AIDS centre in Odessa oblast that says “people under the influence of drugs or alcohol are not welcome.”

I had an easier experience than many people—I gave blood in an anonymous testing clinic, and I had taken time to try to prepare for the results. I still wasn't ready—when the nurse told me my test was positive, I just started to cry. But she did not tell me that there were special tests that could help me monitor my immune system, that there were medications that might keep me healthy, or about the difference between HIV and AIDS. You gave your blood and got your test, and that was all the help you got. I kept returning to the clinic just to wait in the hallway to see if I could find another HIV-positive person who would talk with me. I was lucky and met a doctor who took me to an organization that worked with people with HIV.

Now it may be a little bit better, because doctors know more—4 years have passed since my diagnosis. But even now, I have to tell people who have HIV about the treatment possibilities—they are not finding out from doctors. Some people may know about triple combination therapy—they come and ask, where can I get it? But triple combination therapy is so expensive. They don't know that they can live a long time without treatment, or that CD4+ counts can help them monitor their immune system. They don't know about viral load tests. No one told them.

There are two things I worry about most with regard to treatment. First, many doctors prescribe monotherapy, so people will develop drug resistance. Second, in Ukraine, all efforts are directed to making antiretroviral treatment available, but no one is talking about medications to prevent AIDS-related infections. In the mass media, at every conference and meeting, the question of medication access is taken to mean antiretrovirals, with little focus on the prophylactic medications. No one is talking about the fact that these medications are cheap, that they are effective, and that they are needed. Even the government could afford them. Meanwhile, people I work with, and people all over Ukraine, are dying from infections that could be prevented.



FOCUS ON CAUCASUS/CENTRAL ASIA

While most CEE/FSU countries offer access to at least one antiretroviral or medication to prevent AIDS-related infections, Caucasus and Central Asian countries are often the exception. Five—Armenia, Azerbaijan, Kyrgyzstan, Tajikistan, and Turkmenistan—all report that they lack all antiretroviral treatment and either low-cost CD4+ testing, PCP prophylaxis, or both. While in some of these countries fewer than 100 people are infected, the epidemic is gaining momentum: in Armenia, UNAIDS estimated that 2 400 had HIV at the end of 2001. Without either low-cost antiretroviral or prophylactic treatment, people with HIV who cannot pay for their own care—including virtually all IDUs—have no tools at all to avoid AIDS-related illness and death.

Other Central Asian countries have instituted somewhat better treatment options. In Kazakhstan and Uzbekistan, for example, with 2 870 and 1 120 registered cases of HIV/AIDS respectively, respondents indicate that low-or no-cost PCP prophylaxis and CD4+ testing is available in Almaty and Tashkent. In addition, 4% of registered HIV/AIDS cases in Kazakhstan and 3% of registered HIV/AIDS cases in Uzbekistan receive some form of ARV (though officials report that no triple combination therapy is available in either). In Georgia, where 316 cases of HIV/AIDS are registered, 3% receive ARV, all of it triple combination therapy. Half of those on triple therapy are IDUs.

Geographical location, even within a single country, sharply affects availability of CD4+ testing and PCP prophylaxis.

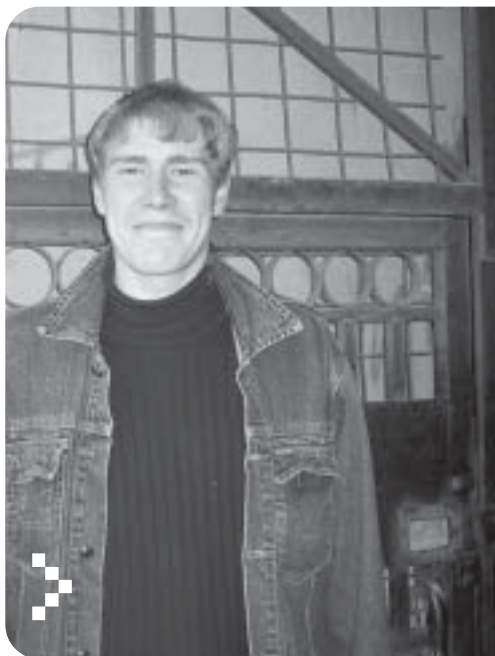
- In Ukraine and Belarus, CD4+ testing and PCP prophylaxis are most available in capital cities, and unavailable in the places where HIV prevalence is highest.
- Russian respondents report greater diffusion of these services, with 11 of 24 oblasts reporting that both

CD4+ counts and PCP prophylaxis are available at low or no cost.

- Urban economic centers do not necessarily offer superior accessibility: in Irkutskaya oblast in Siberia, for example, a harm reduction program reports that clients have access to PCP prophylaxis and regular low-cost CD4+ testing, while another from St. Petersburg says its clients cannot access PCP prophylaxis at low or no cost (see Fig. VI).

Figure VI: Accessibility of PCP Prophylaxis and CD4+ Testing by Location, April-May 2002

Country	City or county/oblast	Percent of total HIV/AIDS cases in country	PCP prophylaxis (some availability at low or no cost)	CD4+ counts (some availability at low or no cost)
BELARUS	Minsk	13,4%	Yes	Yes
	Gomel oblast	65,7%	No	No
UKRAINE	Kiev	3,5%	Yes	No
	Donetsk oblast	22,5%	No	No
RUSSIA	St. Petersburg	7,8%	No	Yes
	Irkutskaya oblast	6,5%	Yes	Yes



Maxim Fedotov, Médecins Du Monde, St. Petersburg, Russia

Four years ago, I went for a physical examination. The doctors play football with you if you are a drug user, passing you from one department to another, like it's already all over, like there's no help for you. Literally, I was told "we don't have time to examine normal people, and you come to bother us?" Of course I didn't go back.

The team at the bus [needle exchange site] told me to go to Botkin hospital for a more thorough examination. It was very good communication with doctors there. They took me as a normal person, not as a criminal drug user. They cared about my HIV positivity, but they didn't make a big deal of it. I was informed about some medical aspects—on how to keep my health well, about diet, vitamins. A little later, they told me about immunograms, CD4+ testing—not a very long conversation, because the doctors are very busy, but a bit of advice. To explain these things completely to a person you need an hour and a half, and people with HIV are very numerous now. One of the members of the needle exchange team, Edic, was already aware about HIV, and he passed that information to those of us in the hospital. I also got a Dutch book translated into Russian that explains very clearly everything about HIV and opportunistic infections.

I work with the team myself now. Twice a week we also go to the Botkin hospital to support people psychologically at the moment they get their positive result and are very frustrated. Our program is not only aimed at HIV-positive patients, but also at the people who are hospitalized because of

Hepatitis B and C who are not HIV-infected. Most of the people who get hepatitis are drug users, so there is a good reason to do HIV prevention work with them. Being positive, it's easier to talk to the people who are negative about protecting themselves, because you have your own experience and your own example.

We also go every week to talk to those who are HIV-positive. It's emotional when you see so many HIV-positive persons being ill, and you imagine that the same thing can happen to you. People at Botkin hospital get everything the doctors can give them—but that doesn't include tri-therapy. Official statistics are that 100 people get triple combination therapy in St Petersburg, but I've seen only one. I think maybe all the rest are people who got infected through medical settings—doctors or health care workers.

As for monotherapy, we have this. Everyone who wants it can take it at the AIDS centre, because it's made here in Russia. It's cheap, but it's more harmful than effective. And I don't know whether the State will act to change, if they will see the epidemic—this terrible problem—not as something in the future, but now, in our everyday life. In the meantime, I take heart from my work in the needle exchange program. I know it is saving people. Here, too, I can look to my own example. All my friends I used to shoot together with, they come now to exchange. And I'm glad to say it—I am the only one of us who is HIV-infected.

Access to Care

Gauging access to basic health care can be particularly difficult in CEE/FSU countries. While such care is often theoretically guaranteed by the state—making it true to say that some is available at low or no cost—the reality may be that free care is in extremely short supply. A recent survey of health care in St. Petersburg makes the point. Though the Russian constitution guarantees free care for all, more than 90% of those surveyed who had sought medical care in the past month had to pay something to see a doctor, often unofficially. Almost a quarter of people paid what was, on average, nearly a week's salary (Brown and Rusinova 2000).

Similar distinctions may be evident in this survey's findings. Overall, 71% of respondents report that some primary care such as treatment of bacterial infections or sexually transmitted diseases is available at minimum or no cost to their clients. IDUs, however, may face particular difficulties in accessing such care.

Half of 115 respondents working directly with IDUs are unable to say how many of IDUs are receiving primary care.

Harm reduction programs (N=42) able to indicate how many IDU clients have access to basic health care report that on average, 73% of their IDU clients have no access to basic care from any source.

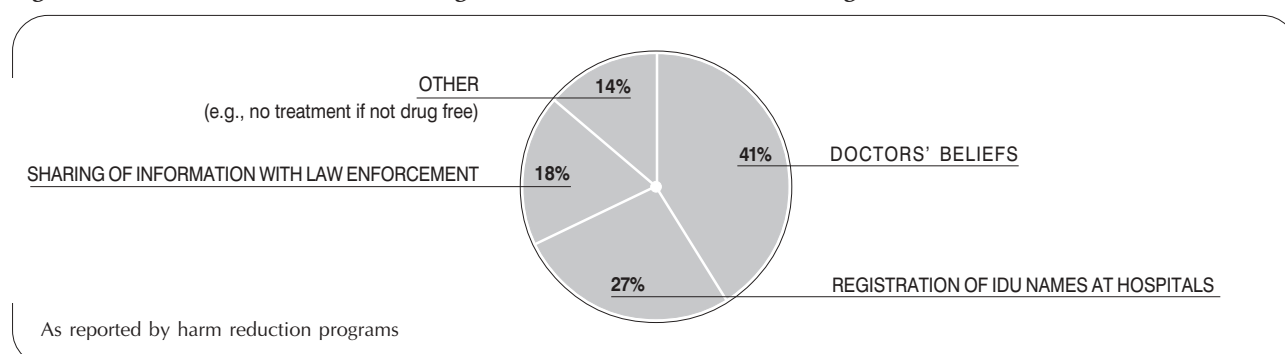
- In Bishkek, Kyrgyzstan, one harm reduction program reports that less than 10% of its 600 clients have access to primary care.
- In cities in Azerbaijan (Baku), Macedonia (Skopje), and Kazakhstan (Aktobe), programs report that none of their IDU clients—nearly 2 000 combined—have access to primary care.

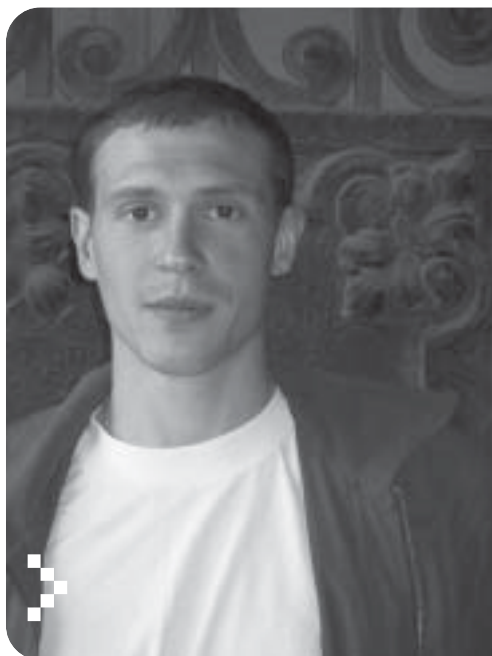
- In Plovdiv, Bulgaria, one program reports that only 15% of IDU clients have access to primary health care. Another, in Pleven region, says 27% of its IDU clients have access to care.
- In Vilnius, Lithuania, one program reports that only 1% of its 3 600 IDU clients have access to primary health care.
- In Tolliati, Russia, less than 1% of 3 680 IDUs in one program have access to primary health care. In St. Petersburg, only 13% of 3 500 IDUs served by one program have access to care.
- In Falesti, Moldova, only 7% of the 274 IDUs in one program have access to primary health care.
- In Uzhgorod, Ukraine, a program working with Roma reports that less than 5% of IDUs have access to primary health care. In Donetsk Oblast, of 4 500 IDU clients, the AIDS Centre reports that only 300 of them—7%—receive primary health care from any source.
- In Dushanbe, Tajikistan, a harm reduction program reports that fewer than one in five (17%) of its 970 IDU clients have access to primary care.

Nearly two-thirds (60%) of 75 harm reduction programs working with IDUs in the region report that drug users are informally discouraged or prohibited from receiving primary health care. Again, harm reduction and government HIV/AIDS programs are sharply divided on this point. Among government HIV/AIDS programs, only 23% of respondents identified such discrimination.

- In Ukraine, 20 out of 24 programs—including government HIV/AIDS and harm reduction programs alike—report that IDUs are informally discouraged or prohibited from receiving care.

Figure VII: Causes of Discrimination against IDUs in Health Care Settings





**Andrei Artemenko, Crossroads of Seven Roads,
Angarsk, Irkutskaya oblast, Russia**

I got permission from the director of the drug rehabilitation centre to go to the AIDS centre in Irkutsk for an HIV test. The doctor who told me, she asked, “so, what result do you expect?” “Positive, of course,” I said. Meaning good, not HIV-positive. She said, “Well, you had a positive test result.” Meaning HIV-positive. She called another doctor who came with a document to sign. They were not unkind, they offered me pity, though at that moment that wasn’t what I needed. I didn’t know what I needed. It was early in my recovery from drugs, and it was early in the HIV epidemic. I was number 723 in Irkutskaya oblast. Today, we have 12 000.

I learned at the same time about all of my problems, urogenital infections, hepatitis. I was very deeply depressed, and they told me, “you have a right to have free treatment here for all pathologies, even for dentistry.” I went back regularly for my teeth. It was a little more complicated when I had to be hospitalized, because the hospital didn’t want to believe that I had stopped drug use. They put me in Department 9, the special HIV area where everyone was an active drug user. The attitude of the staff was “oh, those poor drug users, they are really hopeless.” They had no idea how to set limits or what to do.

People were selling and shooting drugs in the hospital beds. For me, it was very difficult, and I heard of some people who actually committed suicide. There was a psychologist on staff, but I never saw him in the time I was there. Other guys said that if even he came, it was only to say he had been there.

I go back now to the HIV ward now to do service. The epidemic is spreading—there are people who aren’t drug users. When I go, I speak with people about my experience. I don’t moralize, but I do share about how I stopped drug use through the rehabilitation centre, how it’s possible to live with HIV, even to find good parts of life if you are infected. At the AIDS centre, I get an analysis, including an immunogram, every six months—I have 700 CD4+ cells, which is lucky. I know that with only three AIDS specialists for 12 000 people in Irkutsk—and no combination therapy—there’s not much they can do for people who are sick.

I’m also working at the rehabilitation centre and with the polyclinics (health clinics), talking with them about how to do more to help active drug users who come there. And I’ve gone back to school for psychology. They can use the help of some qualified people who have also learned through experience.

- In Russia, nine out of ten government HIV/AIDS programs say that IDUs are treated the same as other patients. Twelve of seventeen harm reduction programs (71%) say IDUs are informally discouraged or prohibited from getting care.
- In Kazakhstan and Uzbekistan, no government HIV/AIDS programs say there is discrimination. All harm reduction programs say there is.
- In Romania and Tajikistan, all programs report informal discrimination.
- In only seven countries—Azerbaijan, Estonia, Georgia, Hungary, Kyrgyzstan, Poland, Turkmenistan—all respondents agree that IDUs are treated the same as other patients. In some of these countries, however, access to care is sharply limited irrespective of whether clients inject drugs or not.

Reasons for discouragement/discrimination against IDUs in primary health care settings include sharing of information between health providers and law enforcement, registration of IDU names on special lists, and physician attitudes (see Fig. VII on page 19).

- In Bulgaria, Kazakhstan, Russia, Tajikistan, Turkmenistan, Ukraine, and Uzbekistan, respondents report that sharing of information between health providers and law enforcement and registration of IDU names are among the causes of discrimination.
- In Lithuania and Macedonia, by contrast, doctors' beliefs are seen as the sole source of discrimination in primary health care settings.



FOCUS ON POLAND

While most countries with high rates of HIV/AIDS among IDUs report limited HIV care and rapidly growing epidemics, Poland offers a powerful counterexample. Since initial outbreaks among IDUs, Poland has managed to contain its epidemic. Survey findings give some explanation as to why:

- 100% of programs serving clients in Poland report no differential treatment between IDUs and non-IDUs in primary health care.
- Half (50%) of all those on ARV have a history of injecting drug use, and all those on ARV are on triple combination therapy.
- 100% of respondents report that CD4+ testing and PCP prophylaxis are available at low or no cost.
- Methadone and syringe exchange programs operate throughout the country with government support.



Grazina Zakiene, Vilnius Center for Addictive Disorders, Lithuania

You hear the same misconceptions about methadone from drug users and doctors alike—that it's even worse than heroin, that it's just replacing one addiction with another. I didn't know much about it myself before I started. But I know that when I was a drug user, I only ever thought about two things—work to get food for my children, and then buying drugs. Methadone got me out of that cycle, helped me do things I never believed I could do—like being a volunteer, or helping other people. I'm on a minimal dose. There's a saying in Lithuanian—choose between two bad things. I chose the one that helped me to return to life.

I work to bring information and clean syringes to people who are still using drugs. We have a bus now, but we started on foot, using public transportation. Since we ourselves are ex-drug users, we know a lot of people, and are allowed into the drug selling points and places others cannot go. I think the counseling and information we bring are as important as the syringes: talking to drug users about protecting themselves, helping people get documents they need, taking people by the hand and leading them to health care if they have ulcerated wounds, hepatitis or are ready to get into drug treatment.

Since I have HIV, I also try to look out for other people who do. I heard about one girl in the hospital, and I went round to see her. She had burns over forty percent of her body from when the drugs she was cooking at home exploded. The doctors acted terribly with her—they refused to give her any pain relievers because she was a drug user with HIV, and were just ripping the

bandages off. I asked some doctor friends for prescriptions for analgesics, and I bought them with my own money and I brought them to this girl. I also went to see the head of the department to complain. "You really want to help her?" he asked me. "Then get a gun and shoot all the drug users, especially the HIV-positive ones. That would be the most helpful thing for them." I went to a journalist acquaintance. The hospital denied everything, but after the story in the newspaper they started to act differently.

You know how in the old days they had lepers? People with HIV are the new lepers, but without the bells. When I first spoke publicly about my infection, my neighbors refused to share the lift with me. Worst of all, there was a special meeting in my children's school, where all the parents were told that their children shouldn't play with my children. My children are not infected, but of course that didn't matter.

After I found about my diagnosis, I could only think that it was God's punishment. I seriously contemplated the "golden shot" (intentional overdose). After that, though, I thought maybe HIV was a sign that I could actually help others. I can sit down and say "poor me," complaining. Certainly there are moments when I cry a lot, but I try to have other people see me with a smile, especially other HIV-positive people. Because now drug users are calling me at home at two or three in the morning saying "I don't want to live." I talk with them and try to give them hope. It gives me hope in return. When you can give back to life, it's an enormous reward.

Substitution Treatment

Substitution treatment—also known as maintenance treatment—is a long-term approach (not less than three months) used to reduce illegal opiate use and the crime, death, and disease associated with drug addiction. Methadone and buprenorphine, the two medications used most commonly in CEE/FSU countries for substitution treatment, are also prescribed on a short-term basis to detoxify those addicted to opiates (including heroin, or homemade preparations such as *cherny* or *kompot*). Most drug users who detoxify, however—no matter what method used—lapse back into drug use. Substitution therapy seeks to reduce or eliminate opiate use by stabilizing addicts for as long as is necessary to help them avoid previous patterns of drug use and associated harms, including sharing of injection equipment (Lindesmith 1997).

The most common treatment, methadone maintenance, has been shown in hundreds of scientific studies to be effective in reducing drug-related harm without negative health consequences. Compared to users of illegal opioids, people who receive methadone spend less time in jail and in the hospital than users of illegal opioids, are less often infected with HIV, commit fewer crimes, and live longer (Gunne and Gršnbladh 1981; Abdul-Quadar, Friedman et al. 1987; Novick, Joseph et al. 1990; Ball and Ross 1991; Ward, Mattick et al. 1994; Lindesmith 1997). The long-term effects of buprenorphine have been less studied, though it too appears to diminish harms associated with illegal drug addiction. In addition, since medications used for substitution treatment are tightly controlled, maintenance treatment brings drug users into regular contact with the health care system, an important element when so many IDUs are infected with HIV.

An estimated half million people receive methadone maintenance treatment (MMT) worldwide, the majority (352 000) in EU countries where methadone is both legal and used to varying degrees (EMCDDA 2001; Solberg 2002). Those European countries where MMT is most widely available, such as the UK, are those where HIV prevalence among IDUs is usually the lowest. In CEE/FSU countries, however, particularly in those countries where IDUs are the highest percentage of total HIV/AIDS cases, use of substitution treatment remains highly limited.

SURVEY RESPONDENTS AND REGIONAL EXPERTS INDICATE THAT:

A total of 6 565 patients in CEE/FSU countries are receiving substitution treatment with either methadone or buprenorphine.⁹

- Of these, 6 343 (97%) are on methadone maintenance and 222 (3%) receive buprenorphine.
- In Russia, where methadone and buprenorphine are illegal, the synthetic opioid Tramadol is used for substitution treatment. Numbers receiving treatment are unavailable.

Cost of substitution therapy for patients, as with ARV medications, is a patchwork, with treatment available for low or no cost, for substantial cost, and even through illegal or unregulated import.

- Methadone, whose annual price in the region ranges from 20-1 150 USD per person, is generally cheaper than buprenorphine, which can cost as much as 4 700 USD per person annually (UNAIDS Vienna Team 2002).

Methadone maintenance treatment is legal and used in 14 of 27 countries surveyed, and buprenorphine is legal and used for substitution treatment in 4 of 27 countries (see Fig. VIII).

- Even those substitution treatment programs serving clients at minimal or low cost are open only to IDUs who have been injecting for two or more years and who have made several unsuccessful attempts to quit.

Where substitution treatment is most accessible, IDUs often represent the smallest percentage of total HIV/AIDS cases.

- 77% of all substitution treatment in CEE/FSU countries is offered in Central and Southeastern European countries where IDUs are less than 15% of total HIV/AIDS cases.
- Croatia and Slovenia alone offer substitution treatment to 3 400 patients, or 52% of all those receiving methadone or buprenorphine in CEE/FSU. In Croatia, IDUs are 13% of total HIV/AIDS cases. In Slovenia, where methadone is available in prison and through pharmacy-based administration, IDUs are 3% of total HIV/AIDS cases.

Where substitution treatment is least accessible, IDUs often represent the highest percentage of total HIV/AIDS cases.

- Nine countries—Albania, Armenia, Azerbaijan, Belarus, Kazakhstan, Russia, Tajikistan, Turkmenistan, and Uzbekistan—offer neither buprenorphine nor methadone maintenance. More than 80% of all HIV-positive IDUs in CEE/FSU live in these nine countries.
- Methadone maintenance treatment (MMT), the cheapest and most effective substitution treatment, is unavailable in seven of the eleven (64%) countries where IDUs are two-thirds or more of total HIV/AIDS cases.
 - No MMT is available anywhere in the Caucasus/Central Asia except Kyrgyzstan, where a pilot program is now offering treatment to eleven patients.
 - No MMT is available in the European Newly Independent States (Belarus, Moldova, Russia, and Ukraine), where roughly 70-90% of more than 250 000 registered HIV/AIDS cases are IDUs.
 - MMT is legal in the Baltic States, though patients currently receive it at low or no cost only in Latvia.
 - Lithuania offers MMT to 400 people, the largest number in any country where IDUs are two-thirds or more of HIV/AIDS cases, though only at substantial cost to patients.
 - Pilot methadone programs are being prepared in three countries where IDUs are two-thirds or more of total HIV/AIDS cases: Georgia, Belarus, and Ukraine.
 - Moldova is preparing to register methadone for maintenance treatment, a first step toward creation of a pilot program.

Substitution treatment with buprenorphine is available to 222 patients in the European Newly Independent States.

- In Ukraine, where 69% of 46 800 registered HIV/AIDS cases are IDUs, 200 patients received substitution treatment with buprenorphine in 2001.
- In Moldova, where IDUs are 83% of the 1 570 registered HIV/AIDS cases, substitution treatment with buprenorphine is offered to 22 patients.

Respondents report significant confusion over the legal status of substitution therapy.

- Even among harm reduction programs working exclusively or primarily with drug users, 31% did not know whether or not methadone was legal in their country or answered incorrectly. With buprenorphine, the percentage climbed higher still—49% either did not know whether it was legal or answered incorrectly.

⁹ Estimates of total patients on substitution treatment range from 6 510 to 6 565.

Figure VIII: Substitution Treatment with Methadone and Buprenorphine, May 2002

Region/Country	Methadone		Buprenorphine		Total receiving substitution treatment with either substance
	Used	Legal	Used	Legal	
Central and Southeastern Europe					5847
Albania					0
Bosnia & Herzegovina		pilot in preparation			0
Bulgaria	•	•			250
Croatia	•	•			2000
Czech Republic	•	•	•	•	550
Hungary	•	•			110
Macedonia*	•	•			350
Poland	•	•		•	750
Romania	•	•			3
Slovakia	•	•	•	•	364
Slovenia	•	•			1400
Yugoslavia**	•	•			70
Baltic States					485
Estonia	•	•			0
Latvia	•	•			85
Lithuania	•	•			400
Caucasus/Central Asia					11
Armenia					0
Azerbaijan					0
Georgia		pilot in preparation			0
Kazakhstan					0
Kyrgyzstan		pilot underway			11
Tajikistan					0
Turkmenistan					0
Uzbekistan					0
European Newly Independent States					222
Belarus		pilot in preparation			0
Moldova			•	•	22
Russia					0
Ukraine***		pilot in preparation	•	•	200
Total reported					6565

* Macedonian estimates range from 300-350

** Yugoslavian estimates range from 65-70

*** Ukrainian estimate as of January 1, 2002. Low-dosage.

Conclusions and Recommendations

Future Research

More detailed information on IDU access to HIV/AIDS treatment and basic health care is urgently needed. Specific recommendations include:

- Comparative assessment of IDU and non-IDU access to HIV/AIDS care, including semi-official health care requiring payments by patients.
- Comparative assessment of IDU and non-IDU access to basic health care delivered at polyclinics and hospitals.

Antiretroviral Treatment (ARV)

IDU access to effective ARV requires urgent attention and dramatic improvement, particularly in countries where IDUs are a high percentage of total HIV/AIDS cases. Specific recommendations include:

- Creation and implementation of clinical guidelines on initiation of ARV, efficacy of monotherapy, and frequency of immune system monitoring.
- Mechanisms to increase availability of low-cost combination therapy, including manufacture or parallel import of generic ARV.
- Removal or repeal of restrictions and guidelines prohibiting ARV for those with a past history of drug use or those on substitution treatment.
- Implementation of treatment standards for active IDUs based on health-seeking behavior, expressed interest in treatment, and stability of drug-using patterns, rather than on broad categories such as “drug-user” or assumptions that all active IDUs are “non-compliant.”
- Physician training on the spectrum of drug use, effective work with IDUs, and interactions between ARV and methadone or other substitution therapies.
- Collaboration between health care providers and harm reduction programs offering social supports proven to increase IDU adherence to treatment.
- Use where possible and appropriate of simplified combination treatment regimens in administration of ARV.

Access to PCP Prophylaxis and CD4+ Testing

IDU access to medications to prevent *pneumocystis carinii pneumonia* (PCP) and to CD4+ testing require urgent attention and dramatic improvement, particularly in countries where IDUs are a high percentage of total HIV/AIDS cases. Specific recommendations include:

- Provision of low- or no-cost medication to prevent PCP.
- Provision of low- or no-cost CD4+ testing.

Access to Primary Health Care

IDUs require dramatically improved access to primary health care (such as treatment of bacterial and sexually transmissible infections) and protection against discrimination in health care settings. Specific recommendations include:

- Confidentiality measures to deter sharing of medical records with law enforcement.
- Physician training on the spectrum of drug use and effective work with IDUs.
- Implementation of treatment standards for active IDUs based on health-seeking behavior, expressed interest in treatment, and stability of drug-using patterns, rather than on broad categories such as “drug-user” or assumptions that all active IDUs are “non-compliant.”
- Collaboration between health care providers and harm reduction programs offering social supports proven to increase IDU adherence to treatment.

Substitution Treatment

Improved access to methadone and other substitution treatment proven to reduce disease, crime, and other drug-related harm is urgently required, particularly in countries where IDUs are a high percentage of total HIV/AIDS cases. Specific recommendations include:

- Education about existing substitution treatment options for both harm reduction and government HIV/AIDS programs working with IDUs.
- Government support for scaling up of existing methadone maintenance treatment (MMT) and implementation of MMT or other substitution treatment in countries where such programs do not currently exist.
- Exploration of cheaper treatment options, including generic products, in countries where methadone or other substitution treatment is available only at substantial personal cost.

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